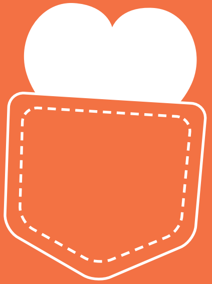
My Big Pocket Guide to Heart Failure

A Patient's Story



Pumping Marvellous
for heart failure patients

Authored by patients like you

HELPING PEOPLE LIVE BETTER WITH HEART FAILURE

WELCOME TO THE PUMPING MARVELLOUS FOUNDATION

They say good things come in small packages, we think that this is a marvellous example.

Our pocket guide will provide you with some initial information, answers, support, and give examples of how you can live life well with a diagnosis of Heart Failure. This "Marvellous Pocket Guide" is as a result of the experience gained by our marvellous team of patients here at the Pumping Marvellous Foundation who started just like you, with a diagnosis of Heart Failure.

We recommend that you explore some of the topics that are raised in this Marvellous Guide, by visiting our website at **www.pumpingmarvellous.org** where you will find other Marvellous Guides, or gain invaluable support from fellow patients and carers at our closed support group on Facebook, just tap into the search bar on Facebook **'Help for Hearts'** where you can apply to enter. If you prefer you can always give the team a ring on **01772 796542**.

All our patients and carers have been where you are, at the start of their new journey, but never forget you are not alone.

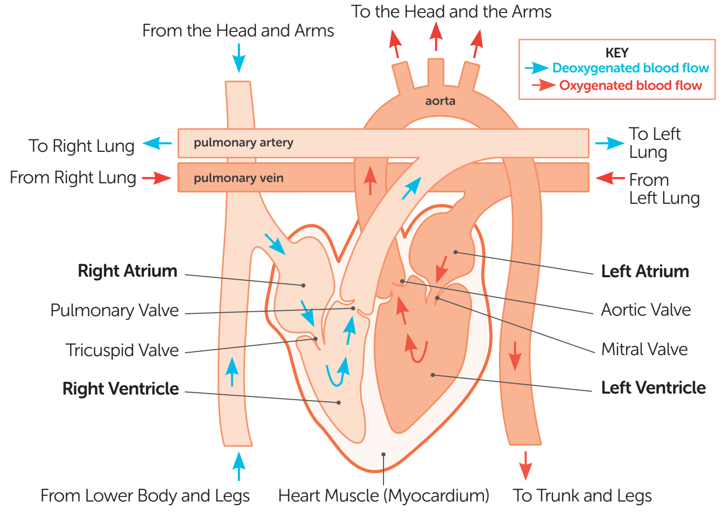
PLEASE NOTE: this booklet should not replace and/or substitute the interactions with and advice you are given by your Healthcare Professional. If you have any concerns about your condition then do discuss them with your Healthcare Professional at the earliest opportunity.

What Does the Heart Do?

The heart is an organ that acts as a pump to send blood around the body. Your blood contains oxygen and nutrients that are needed by every part of your body in order to function. Clench your two fists together and that's about its size; it sits in the centre of your chest tipping down to your left-hand side. It has different layers (one of which is made of muscle), so the heart can squeeze the blood out. It is told when to pump by a nerve that triggers the heart's own electric system.

The heart delivers the blood via arteries and it is then returned via veins. Think of it as a motorway system. The diagram shows the inside of the heart. It is made up of four chambers: on the right-hand side, blood returns from delivering oxygen around the body by the veins (a motorway), the heart then sends the blood to the lungs (petrol station), picks up oxygen and returns to the left side of the heart which then delivers the blood to the body via arteries (another motorway). Note from the diagram the little gates letting the blood move from one chamber to another; these are called valves. Every time this occurs, it is called a beat.

As with a car the heart needs to be looked after in order for it to do its job effectively.



Why Have I got Heart Failure?

No one likes the word failure. The Pumping Marvellous Foundation was started with the mantra to be positive around Heart Failure, so let's start by saying that you are not a failure. If you have been told you have Heart Failure, then it means that your heart is failing to pump as efficiently as it should, in order to supply the body with the oxygen and nutrients that it needs. You may hear technical terms to describe this as Heart Failure with reduced Ejection Fraction (HFrEF). There is another common type of heart failure whereby the heart fails to relax and fill efficiently called Heart Failure with preserved Ejection Fraction (HFpEF). The question to ask to your Doctor or Nurse is: "What type of Heart Failure do I have?" and "Why is my heart not working efficiently?"

If you have HFpEF, ask your Doctor or Nurse for our "Marvellous Guide to Heart Failure with preserved Ejection Fraction" as treatments are different than the other type of Heart Failure, HFrEF. You can also download it from our website, in the Community Hub area under the Support Guides section, it's the fuchsia pink-coloured booklet.

There is generally a reason why the heart is not pumping correctly. The most common reason is that the heart muscle has been damaged by a poor blood supply such as after a heart attack. Other causes include:

- High blood pressure
- Type 2 diabetes
- A virus that has affected the muscle of the heart
- As a result of the heart's rhythm being abnormal for example, atrial fibrillation (AF)
- A genetic condition which may have affected the muscle of the heart as in cardiomyopathy
- Excessive alcohol intake
- The valves of the heart being damaged
- Some types of chemotherapy
- In rare cases, a form of Heart Failure in pregnancy or just after delivery called peripartum cardiomyopathy.

On very rare occasions we are simply unsure of the cause, however your Clinicians will be doing their best to find out the cause.

Your treatment will consist of therapy in order to correct or modify the underlying causes of your Heart Failure as well as improve the efficiency of your heart.

To understand what treatments and care you should be given, please visit our Patient Charter: pumpingmarvellous.org/community-hub/patient-charter

How do Doctors know I have Heart Failure?

You may have had a number of symptoms which may have been distressing. Some of these may be:

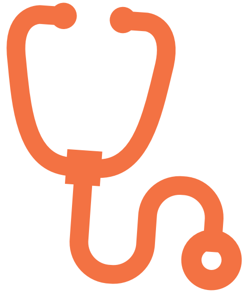
- Breathlessness, particularly on activity, or lying down, resulting in you waking up at night gasping for breath
- Fluid gathering (swelling) in your feet, legs or tummy
- A cough, particularly at night
- Feeling very tired and lethargic
- Feeling dizzy, lightheaded and maybe a little confused

These symptoms may have been severe and led to you being admitted in to hospital where you may well be reading this guide. Often your symptoms have developed gradually or you may have had a sudden onset of symptoms, causing a rapid deterioration in your health.

So How Bad are Things?

We are aware that Heart Failure is a serious condition, however the important thing to remember is that there is now a good understanding of it, and that there are a number of treatment options available; from medication to cardiac devices, to help manage it. Like many other conditions the relentless challenge of discovering newer treatments is always on the horizon.

What Tests Have I Had, or Will Have to Undergo?



Think of it as jigsaw pieces being put together to reveal a picture of what has been going on. At this stage it's very important you help give the Doctor the whole picture. You may feel uncomfortable discussing what's been going on if you feel negatively about it. In our experience telling them everything will lead to the picture being built up quicker.

This is a very important part of self-managing your condition; being able to have an open and honest conversation with your Doctor or Nurse (whether it be before diagnosis or all the way through your treatment) is so important. If this is the only thing you pull from this Marvellous guide then this is the nugget to understand.

Regarding your tests and investigations these are some of the examples you may or may not have encountered:

- Your Doctor will have asked you a number of questions about what has been happening to you now and in the past.
- Your Doctor will have given you a physical examination.
- You may well have had a number of blood tests to show if your heart is perhaps struggling by measuring 'natriuretic peptides'. These are proteins released by the heart when it is under strain, sometimes referred to as NT-proBNP or BNP. The blood test may also be checking if your kidneys or liver are functioning well, ensuring you are not iron deficient or anaemic, and that your thyroid gland is working well. You may have had these done on a number of occasions and your health team will no doubt be repeating them to make sure everything is going well.
- You will have had a tracing of the heart – an ECG. This can give a great deal of information, it can show if your heart is going too fast or to slow, if it is in an unusual rhythm and what has happened to the heart in the past.
- Echo (echocardiogram) – this is a scan of the heart and is vital to show how your heart is pumping, if the heart's structure has been affected in any way and how the valves are working. It is able to measure how much blood your heart is pumping to the rest of the body, this is called the ejection fraction. A normal ejection fraction is approximately 55%. Heart Failure with reduced Ejection Fraction (HFrEF) generally means your ejection fraction is 40% and below. What matters is how you are feeling, not the numbers. To learn more about having an Echo, visit our website and download our "Marvellous Guide to Having an Echo" from the Support Guides section, it's the dark-purple-covered booklet.

You may have further complex investigations as you go along, more details can be found on the Pumping Marvellous website.

Can They Cure My Heart Failure? How Will They Treat Me?

This is a question you will need to discuss with your Doctor or Specialist Nurse, as it depends on what has caused your heart to pump inefficiently. What is important to remember is that there are various treatments to support your heart to work more effectively, which can ensure you live your life well. You have a big role to play in that process. This guide will give you some tips and will share some of our tried and tested self-management tools that will ensure you get the best from your treatment and that you find your new normal as soon as you can. Remember, Heart Failure is treatable.

Tablets, Tablets and a Few More Tablets!

Yes, you will be asked to take a number of tablets - but remember they are there to do a job, and have a positive role in improving your health and well-being.

Top Tips - Your Relationship with Your Tablets!

- They may take some getting used to, and you may feel worse before you feel the benefits, stick with it and discuss any concerns with your health team.
- They all have a job to do, so don't worry if you have to take a number at once, the body can handle it.
- You are in charge of your tablets, get into a routine that works for you. Understand what they are and how they are going to help you.
- A number of your tablets have to be increased on a gradual basis, and you will have your blood pressure checked and blood tests taken between each increase. So it can be a tedious process, but stick with it, you will see the positive benefits.
- Try not to miss taking them and never stop taking them. Remember it is a partnership between you and your Doctor or Nurse. Do discuss with your Doctor or Nurse any problems when you see them, but don't hesitate to contact them at any time with any concerns you may have.

What Tablets Will I Be On?

Different people will be on different tablets at different dosages, but below are some of the key medications you are likely to find yourself on. The following is not a complete list of any side effects with your tablets but serves as a general guide. If you have any concerns do speak to your health team.

Beta Blockers - often end in 'lol' - e.g. Bisoprolol, Carvedilol

These tablets make your heart beat slower but stronger, and are started at a low dose and increased slowly to the optimum dose, or one that you are comfortable with. They may make you feel weary at first; occasionally they can slow down your heart too much and make you feel lightheaded.

ACE Inhibitors - often end in 'pril' - e.g. Ramipril, Lisinopril, **or ARBs (often end in 'sartan')**

These tablets ease the workload of the heart by relaxing the blood vessels around the body, which reduces the strain on the heart. Occasionally they may give you a dry, irritable cough at first which often settles, however if this persists, particularly during the night, mention it to your Doctor or Nurse. They do lower your blood pressure so that will be checked as the tablet is increased and may affect how your kidneys work so a blood test will be taken again as the tablet is increased.

Should the ACE Inhibitor give you persistent problems with a cough then an alternative can be prescribed called an ARB (Angiotensin Receptor Blocker), these often end in 'sartan'- e.g. Losartan, Candesartan. They work very similarly to an ACE Inhibitor but should avoid any problems with a dry cough.

Diuretics (water tablets)

- Mineralocorticoid Receptor - Antagonist (MRA) like Spironolactone / Eplerenone. These are evidence based and typically have less diuretic effect but have other actions which protect the heart.
- Loop Diuretics like Furosemide / Bumetanide / Torsemide. Loop diuretics are used specifically for fluid retention and frequently people with Heart Failure. They will vary on dose depending on symptoms and weight

These tablets help the body to get rid of any extra fluid that may have built up (in your lungs, feet, legs or stomach) which will ensure that there is less fluid for your heart to deal with. You may be on one or more different types of water tablets as they work in different ways on the kidneys e.g. Furosemide, Bumetanide, Spironolactone, Eplerenone. The difficulty is that they will make you have to pass more water, so be prepared for frequent trips to the toilet. But they will ease your symptoms. If you are admitted to hospital due to a good deal of fluid that has built up in your body, then you will be given Diuretics via a drip. They can make your skin dry, and upset your kidneys, so again expect frequent blood tests.

Digoxin

Digoxin is occasionally used in Heart Failure, but may also be used to control the rhythm of the heart.

Ivabradine (also known as Procoralan or Corlanor)

This drug is used on top of, or instead of, a Beta Blocker if you have a normal heart rhythm, but a heart rate that is greater than expected when you are at rest.

Sacubitril Valsartan (also known as Entresto)

The NHS in England, Wales, Northern Ireland and Scotland all have a slightly different brief to prescribing this tablet. It may be prescribed to replace the ACE or ARB you may already be on, however, sometimes it may be considered without first prescribing an ACE or an ARB. Sacubitril Valsartan blocks certain enzymes which may strain your heart and enhances the protective systems that support your heart. It can lower your blood pressure and affect your kidneys, so again frequent blood pressure checks and blood tests are required as the drug is increased.

SGLT2 inhibitors are an important addition to your standard treatment of symptomatic chronic Heart Failure with reduced ejection fraction. They are:

- Well tolerated by patients
- Can be prescribed by your GP or Heart Failure specialist

SGLT2 inhibitors are a group of medicines used to treat insufficiently controlled type 2 diabetes and now symptomatic chronic Heart Failure with reduced Ejection Fraction. They may also be called "Sodium-glucose co-transporter 2 inhibitors" or just "gliflozins".

Dapagliflozin and Empagliflozin are currently approved for use in symptomatic chronic Heart Failure with reduced Ejection Fraction whether you have type 2 diabetes or not.

What do they do?

SGLT2 inhibitors have shown benefit to patients with Heart Failure caused by a pumping problem with their heart (HFrEF – Heart Failure with reduced Ejection Fraction). If a patient is experiencing Heart Failure symptoms despite being on optimised therapy, a GP may, on the advice of a Heart Failure specialist, prescribe an SGLT2 inhibitor as an additional medication to their standard treatment. In addition to improving symptoms, clinical trials of SGLT2 inhibitors have shown a reduced possibility of being admitted to hospital with Heart Failure and also an improved length of life.

Other reasons for being prescribed

In insufficiently controlled type 2 diabetes, SGLT2 inhibitors are prescribed to reduce blood sugar levels but in clinical trials also reduced admissions to hospital with Heart Failure. More recent trials have shown they are also beneficial to patients with symptomatic chronic Heart Failure with reduced Ejection Fraction, despite being optimised on standard Heart Failure medication.

What are the most common side effects?

SGLT2 inhibitors are well tolerated. 1Common side effects include dizziness, rash, back pain and increased frequency of passing urine. If the patient has diabetes then thrush (candidal genital infection), urinary tract infection and a more unusual side effect known as diabetic ketoacidosis (DKA) may also occur. 1 www.nice.org.uk/guidance/ta679 / www.nice.org.uk/guidance/ta773

Patients with DKA are unwell and may experience excessive thirst, sickness, tummy pain and a sweet smell on their breath in addition to feeling tired or confused. Consult your Heart Failure team or GP if you are concerned with any side effects you may be experiencing.

How do I take them?

You may need blood tests to monitor how you react to the medication, mainly concerning kidney function and blood sugar levels. If you already have diabetes, some adjustment to your usual diabetic medicines may be necessary to ensure that your blood sugar levels do not go too low. Dapagliflozin and Empagliflozin, for example, are both one tablet per day medicines and you may take them any time of the day, but it is best if you take them at a regular time each day. Dapagliflozin and Empagliflozin can be part of your "Sick Day Rules". Please discuss this with your healthcare professional.

Acknowledgement – We would like to thank Dr Jim Moore, GPSI Gloucestershire Heart Failure Service for his review of this section about SGLT2 inhibitors.

Treatment Table

Treatment Name	Maybe called	Prescribed by	What it does
Beta Blocker ends in "lol"	Bisoprolol, Carvedilol	GP or Heart Failure Specialist	Make your heart beat slower and stronger
ACE Inhibitor ends in "pril or ARB ends in "sartan"	Ramipril, Enalapril, Lisinopril, Candesartan, Losartan	GP or Heart Failure Specialist	Relax blood vessels to reduce strain on the heart
Mineralocorticoid Receptor Antagonist - MRA	Spironolactone, Eplerenone	GP or Heart Failure Specialist	Reduce excess fluid build up
Loop Diuretics	Furosemide, Bumetanide, Torsemide	GP or Heart Failure Specialist	Reduce excess fluid build up
SGLT2 inhibitors (sodium-glucose transport protein 2 inhibitor) or ending in "gliflozins")	Dapagliflozin Empagliflozin	GP or Heart Failure Specialist	Improve symptoms and reduce absorption of sugar in the kidneys
ARNI (Angiotensin-Receptor-Neprilysin inhibitor)	Sacubitril Valsartan (Entresto)	Heart Failure Specialist	Enhances protective systems that protect your heart. Lowers blood pressure
Hyperpolarization-activated Cyclic Nucleotide-gated (HCN) channel blockers	Ivabradine	Heart Failure Specialist	Reduces heart rate when rate is more than expected when in normal rhythm
Internal Cardiac Defibrillator	ICD	Heart Failure Specialist	See next page
Cardiac Resynchronisation Therapy	CRT-D or CRT-P	Heart Failure Specialist	See next page

These are the most common tablets that will be prescribed, however depending on why you have Heart Failure, other tablets may be prescribed. A good area for patients and their families to look at medicines is the NHS choices website.

Will I Need any Surgery or Pacemakers to Help with My Heart Failure?

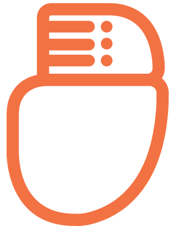
Your Doctor or Nurse will discuss your suitability for any other options open to you, but specialised pacemakers may be recommended. They are likely to be the following:

Cardiac Resynchronisation Therapy – CRT

Depending on the results of your ECG, echo and your symptoms then you may be recommended for this form of cardiac device, which is a type of pacemaker. A small incision is made in the skin, making a pocket in the fat below the skin, usually above the left breast, for the device to sit into. They send tiny electrical signals to the heart to help it beat in a more synchronised way, ultimately ensuring that the heart pumps more efficiently and hopefully making you feel better with less symptoms.

Implantable Cardiac Defibrillators – ICD

Not only does the heart have a beat but also a rhythm. Occasionally the heart can go into dangerous and even fatal rhythm which requires the ICD to deliver a small electrical shot to the heart in order for it to return to a safer rhythm. An ICD is implanted in the same way as a CRT device. On occasions the two different devices are combined together which are called CRT-D.



See our "Marvellous Guide to Having a Cardiac Device Fitted". Ask a member of your health team for a copy or visit our website pumpingmarvellous.org and go the to the Community Hub area under the Support Guides section, it's the yellow-coloured booklet.

The Art of Self-Management

Believe us when we say we know this is a lot of information to take on board, especially when you've so much to deal with already.

The information you have read mainly concerns what others need to do to help you. This next section is how you can help yourself. We feel it is the most important section as it is how you can help make yourself feel better.

We wish we had a magic wand but we don't. The key to self-management is getting yourself into a winning positive attitude by being determined, having a can-do attitude and being resilient to what sometimes feels like a roller coaster ride of ups and downs.

You may very well be feeling overwhelmed at this time. Our patients tell us of a range of emotions they experience upon being diagnosed; from feeling very alone, to a sense of relief – that although they have been feeling so ill for some time, at least now they know what it is and things are beginning to get sorted.

Firstly, you are not alone. Being told you have Heart Failure can be very distressing and it may be some time before you feel you are coming to terms with things and are able to share your emotions. Take your time, take in information at your pace.

Visit our website, where you will find two guides that may help you in the academy and patient academy sections: our **"HOPE"** guide and our **"Walking a Day in My Shoes"** guide.

We believe you'd agree that being diagnosed with Heart Failure is difficult enough to get your head around, but having to navigate your way through what care and support you should expect is a completely new problem. We believe our map will give you a good overview of what you may encounter and answer those questions you might find tough.

Visit our Patient Charter to understand what treatments and care you should be given:
pumpingmarvellous.org/community-hub/patient-charter

Is There Anything I Can Do to Help My Condition?

Yes there is, and this is where we at Pumping Marvellous like to put on 'our positive pants'. We believe in the concept of self-management. This is not just education on Heart Failure and the goals of medical treatment, but how you can successfully monitor and manage your symptoms, and deal with the psychological and social implications of your condition. By successfully self-managing your condition we know this helps you be in control of things and help you to achieve a quality of life that suits you. Heart Failure is serious, but there is a lot of understanding and treatment out there to help you. So put on your positive pants, we are off to New York!

Well, not quite, but one of the symptoms that people feel with Heart Failure is lack of energy. Think of it as a battery that supplies you with your day's energy. You have to use it wisely to get you through the day. How much energy you have in your battery is assessed on the New York Heart Association Scale, so you can gauge where you are in New York each day.

So Where Are You in New York?

A strange question perhaps, but patients and Healthcare Professionals often find the **New York Heart Association (NYHA) Classification Scale** useful in assessing this condition based on the symptoms you are experiencing.

So where are you on this scale today? We should let you know that you may move around on the scale as your condition and treatments change.

The NYHA Scale

The NYHA scale is usually used by Clinicians to assess you. However as you are the only one who knows how you feel, it's a great tool to help you explain to Clinicians what's been going on whilst they aren't there.

NYHA Class	Symptoms
Class 1	No limitation of physical activity. Ordinary physical activity does not cause undue tiredness, palpitations, or shortness of breath.
Class 2	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in tiredness, palpitations, or shortness of breath.
Class 3	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes tiredness, palpitations, or shortness of breath.
Class 4	Unable to carry out any physical activity without discomfort and tired and short of breath even at rest. If any physical activity is undertaken, discomfort increases.

CLASS 1

"I can perform all physical activity without getting short of breath, tired, or having palpitations."

CLASS 2

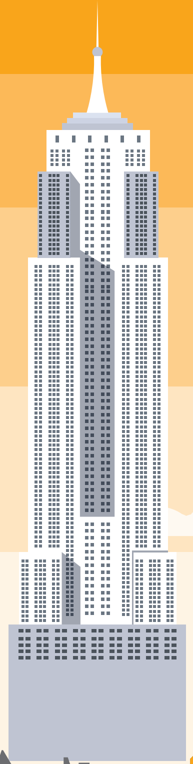
"I get short of breath, tired, or have palpitations when performing more strenuous activities. For example, walking on steep inclines or walking up several flights of steps."

CLASS 3

"I get short of breath, tired, or have palpitations when performing day-to-day activities (for example, walking along a flat path)."

CLASS 4

"I feel breathless at rest, and am mostly housebound. I am unable to carry out any physical activity without getting short of breath, tired, or having palpitations."



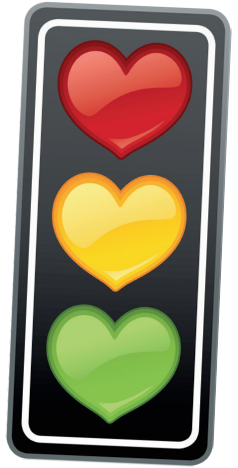
Symptom Checker

Manage your symptoms by using our traffic lights system so that you know what to do if you are hitting any problems.

Plan your activities around your energy levels, these may include your work, social life, or your sex life.

Pace yourself through your various activities, it's often a case of doing the same things that you were used to but at a slower pace. In time you may find your activity levels increase and you find your new normal.

Your Daily Routine



Make sure you **take the prescribed tablets for your heart.**

When you get up in the morning, **weigh yourself** after going to the toilet for the first time. Write this down and **compare it to yesterday's weight. If there is a change, look at the traffic lights.**

Eat a balanced diet and don't add salt. Don't use low salt alternatives.

Check for either reduced or increased swelling in your feet, ankles, legs and stomach.

Ask yourself if your **breathing pattern is the same as normal.**

Balance exercise and rest; **know your limits.**

This Marvellous Symptom Checker has been put together by the Pumping Marvellous Foundation and developed with NHS Heart Failure teams and patients from Staffordshire.

HOW ARE YOU?

Your weight has not increased or your weight had increased by 4lb/2kg over 3 days but you agree with the statements below;

1. **You are no more breathless than usual.**
2. **Your ankles are no more swollen than usual.**
3. **You are as active and mobile as you normally are.**
4. **Your main carer's health is unchanged.**

WHAT SHOULD YOU DO?

There is no need for a review by the Heart Failure specialist team/ GP/Practice Nurse apart from your regular reviews. However, you should be reviewed at least twice a year.

HOW ARE YOU?

Your weight has increased/has increased by 4lb/2kg over 3 days and/or and one of the statements below is true;

1. **You are feeling more breathless than usual.**
2. **Your legs are more swollen than before.**
3. **You are breathless at night or need more pillows to sleep on.**
4. **You are unable to be as active as usual/you are a bit more muddled than usual.**
5. **Any of your other conditions are worsening.**
6. **Your main carer is becoming more ill and unable to help look after you as much as before.**

WHAT SHOULD YOU DO?

Try simple measures to improve your symptoms **and/or** consider an earlier appointment with the Heart Failure specialist team/GP/Practice Nurse if you feel it necessary.

HOW ARE YOU?

If over 3 days your symptoms continue to worsen, **or** if you have other symptoms below consider phoning your GP or the urgent contact numbers below.

1. **You have had diarrhoea or vomiting for more than 24 hours.**
2. **Your carer becomes very ill/has been admitted to hospital and is unable to take care of you.**
3. **You have worsening or new angina.**
4. **You have worsening breathlessness or leg swelling or are unable to be as active as usual.**
5. **If your medication has been reduced but not by the Heart Failure team.**
6. **You have symptoms of an infection and/or you feel very unwell.**
7. **Any of your other medical conditions are continuing to worsen.**
8. **You have blacked out.**
9. **You have become confused about your medications.**

WHAT SHOULD YOU DO?

Contact your Heart Failure team or GP as soon as possible, or consider calling 999 if you feel very unwell.

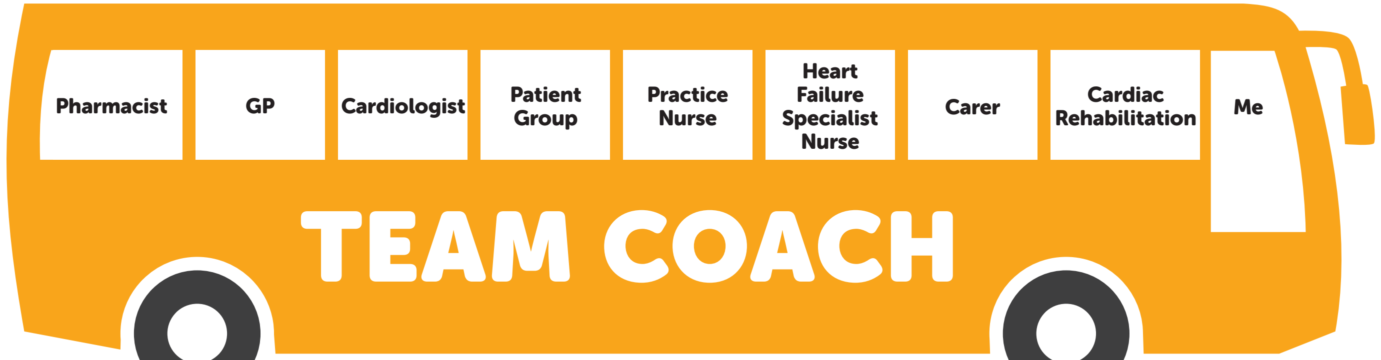
General Tips and Advice

- Try and keep active, ask your health team if there are Heart Failure rehabilitation classes in your area. Every muscle responds well to exercise and your heart muscle is no different. It also ensures that your body generally works more efficiently thereby easing the workload of the heart. Why not hear from our patient community on the benefits of attending cardiac rehabilitation? Search for Pumping Marvellous on YouTube where you'll find a video produced by patients to help you.
- Eat a healthy diet, again seek out support from your health team around any specific needs you have.
- If you smoke, give up. There is a wealth of information and support, see our information page for advice and support to help you.
- If your Heart Failure is due to excess alcohol intake then you must stop, again information can be found at the end of this guide. General recommendations are drink within the recommended safe limits.
- Keep an eye on your salt intake, as high salt intake keeps fluid on board and raises blood pressure. Look out for the salt label on foods and avoid those that show as red.
- You may be given instructions by your Doctor or Nurse on restricting your fluid intake, you will need to discuss this with them.

Develop Your Team

Many of our patients and their carers and families tell us of the great support they get via our **Facebook group Help for Hearts.**

The carer, be that your partner, child, parent, neighbour or friend will often be the most important person in your support team. Remember they will also need help to come to terms with your condition so we have written a marvellous guide especially for them. To learn more about being a carer for a person living with Heart Failure, visit our website and download "My Marvellous Guide to Caring for Heart Failure Patients" from our website, in the Community Hub area under the Support Guides section, it's the mauve-coloured booklet.



The Marvellous Heart Failure Specialist Nurse

You may have been referred to a Heart Failure Specialist Nurse. Our patients and their carers tell us of the invaluable support these Nurses provide. Many Specialist Nurses will be able to examine you, prescribe your medication, order and interpret investigations, support you on the challenges of your condition and direct you to other services you may need. It's good to form a rapport with your GP practice as well.

If you have not got a Heart Failure Specialist Nurse, ask your GP or Consultant if you can be referred to one.

Pharmacists

Pharmacists occupy an important role in helping you manage your Heart Failure. They occupy roles within the hospital, GP surgeries and of course high street pharmacies. They are generally more accessible than your GP and if you need help with medications or you feel you need a review of your current medications, a pharmacist can help. They are also instantly accessible when you have questions about over the counter medications and if they are safe to take with your current medications.

Cardiac Rehabilitation

Scan me with your smartphone to view our videos on YouTube

Scan Me

Cardiac rehabilitation is an important part of helping you live well with Heart Failure. It can make a real difference to how you feel day to day, improving your confidence, wellbeing, and quality of life.

You are not alone — many people with heart failure find that having the right support and guidance helps them feel more in control and more confident about the future.

Cardiac Rehab supports you with things like; Safe & tailored exercise, Practical nutrition advice and skills to help you manage your condition.

Across the UK, Cardiac Rehabilitation is recommended as part of routine care for people living with Heart Failure.

To support NHS Cardiac Rehabilitation services, Pumping Marvellous has created a free, lifelong digital Cardiac Rehabilitation programme, approved for use within the NHS.

By scanning the QR code with your phone, you can go straight to our website and sign up for free.

Getting the Most Out of Your GP and General Practice

We have a number of patients who are willing to support both the charity and other patients. We call these experts Patient Educators. Pierre is one of our Patient Educators; read his advice on forming a good relationship with your GP.

"I feel that where Heart Failure is concerned, it is key to have the right GP. This is vital as he/she is the main day-to-day contact any Heart Failure patient has.

Strike up a good relationship with the receptionists as they can help you a lot with prescriptions, appointments, etc.

Be an educated patient i.e. know about the condition and how it affects you. Know your medication and what it does for you and how it works to improve your condition.

Try not to come across with an attitude of 'there's nothing they could tell me about Heart Failure'. Remember, they are part of your team and are trying to help you.

Choose the right Doctor for you within the practice. This is a bit like an interview process, but really you know who the good ones are from, well, the not so good ones. The one you feel best about, I don't mean the one who you know, the one you can get to agree with whatever you are saying, but the one who will work to do their best to maintain and improve your condition and at times push and encourage you.

If you are lucky enough to have a Heart Failure Specialist Nurse, point this out to them, as the Doctors do not know everything about your condition. This will help your Doctor as they will know that the Nurse is in partnership with them. If there are any issues, there is a good source of information and advice a patient can access. Here is an example: my kidney function was abnormally high and my Doctor said that they would stop one of my tablets, Spironolactone. I said I would give the Heart Failure Specialist Nurse a ring just to get their thoughts on it, which he had no objection to as he felt more informed and valued advice from a specialised Heart Failure Nurse would be great. I fed back the information and didn't stop Spironolactone. My Doctor was very pleased as he recognised that, as a team, the correct decision was made for the patient."

Pierre's Key Tips

1. Explain to your Doctor/practice that due to your condition you would like to see the same Doctor at all times.
2. This may be difficult in emergencies, but if it is an emergency for a Heart Failure patient, in reality the GP would not be the first port of call.
3. Discuss your current symptoms with your Doctor and how together you can both work to improve your health. Discuss access with your Doctors as seeing the same Doctor enables you to build up a good relationship. If you feel you need to see your Doctor, ask if they wouldn't mind you ringing to get a telephone appointment. Quick access can make a big difference in Heart Failure. It is very reassuring knowing you have that facility available to you.
4. Where Heart Failure is concerned, it is key to have the right GP, which in turn helps the self-management process.
5. Work with your Doctor if they have suggestions e.g. on healthy lifestyle options, different medications. Do not dismiss this as they may offer a good solution to help improve your condition.
6. Heart Failure patients are just normal people and normal people have normal problems. A good relationship with your Doctor and GP practice will no doubt be better for you.

What about Welfare Rights and Benefits?

We want you to know that we understand this can be a tricky part of managing your life going forward. We know through our own experiences that you can get what you deserve and that being comfortable and knowledgeable about the system is significantly helpful.

You will also be aware that the benefit landscape is changing all the time, therefore we will keep this page light on information whilst pointing you to the correct websites.

For further information, please visit the government website:
www.gov.uk/browse/benefits

The Citizens Advice Organisation may also provide advice:
www.citizensadvice.org.uk/benefits/

If you or your carer require additional input, support or equipment to enable you to manage, please visit the following website where you will be directed to social services in your area for a free assessment:
www.gov.uk/apply-needs-assessment-social-services

When making a claim for any benefit, it's important you give as much detail as possible as to how your ill health/ disability impacts your daily life. This includes the help and support you need to complete basic daily tasks (even if you do not get that help). You should also provide examples where you can; this should ensure the decision-maker gets a clear picture of the impact your health has upon you on a daily basis.

One Step at a Time

We hope that our Marvellous Big Pocket Guide has triggered thoughts around some of the questions you may have. We know this is not a position you want to be in but it's about taking small steps, which is a good thing. You may never have had to deal with something like this but if you want to then self-management can be the key to a better life and enable you to find your normal again.

This may be the start of your journey so if you need help do seek out further advice from your Healthcare Professional or visit our website
www.pumpingmarvellous.org

Other 'Marvellous Guides' in the Series

All guides are written by patients and clinically validated for accuracy by leading UK Heart Failure specialists.

Scan me!

Please scan this QR code with your smartphone:

Or visit pumpingmarvellous.org

The Wonders of Social Media

At Pumping Marvellous we know how important it is for patients to get support from other people who have Heart Failure, to share experiences, knowledge, feelings and emotions, the negatives and positives of Heart Failure, and yes there are positives. People find successes in Heart Failure as they learn to manage the challenges of Heart Failure. Pumping Marvellous has looked at using new and exciting ways of providing patient to patient support. Why don't you give some of them a try! Search "help for hearts" on Facebook, or search Pumping Marvellous on YouTube as well as the Pumping Marvellous website. In everything we do you will find rich veins of support to help you manage your Heart Failure better.

Good luck, good health and keep those positive pants on!

Important Pumping Marvellous Contacts

- ☑ Website - www.pumpingmarvellous.org
- ☑ Email - hearts@pumpingmarvellous.org
- ☑ Office Tel - 01772 796542
- ☑ X - @pumpinghearts
- ☑ Facebook Support Community - Search 'Help for Hearts'
- ☑ YouTube - Search Pumping Marvellous

My Team

Your Carer's Name:

Your GP's Name:

Your Cardiologist's Name:

Your Heart Failure Nurse's Name:

Your Practice Nurse's Name:

Your Pharmacy's Name:

Your Carer's Telephone Number:

Your GP's Telephone Number:

Your Cardiologist's Telephone Number:

Your Heart Failure Nurse's Telephone Number:

Your Practice Nurse's Telephone Number:

Your Pharmacy's Telephone Number:

Other Team Details

How can you support us?

Your support gives the Pumping Marvellous Foundation its energy in supporting people and their families. The support received contributes significantly to the organisation's efforts to help heart failure patients.

Educational Support

Delivered to patients and their families through the NHS

Save Lives, Fund Our Guides

Scan the code or visit: **qr.pumpingmarvellous.org/EducationGuides**

Support our National Campaign

Increase awareness of Heart Failure, get faster diagnosis, and get better support living with Heart Failure. BEAT HF, our National Campaign

Scan the code or visit: **qr.pumpingmarvellous.org/SupportBEAT**

Fundraise

Raise money to help people like you and your loved ones. We can help you realise your idea.

Scan the code or visit: **qr.pumpingmarvellous.org/FundraiseNow**

Remember us in your Will

Gifts in your Will can make a huge difference in our ability to transform support to people with heart failure and their families.

Scan the code to place us in your Will or visit: **qr.pumpingmarvellous.org/MakeAWill**

Shape our ideas with your experiences

The Pumping Marvellous Foundation, driven by patients' needs living with heart failure, we never have enough ideas. Come and join our 'Marvellous Patient Educators" and make positive changes.

Scan this QR code to join our Patient Educators or visit: **qr.pumpingmarvellous.org/PatientEducator**

If you have any concerns or questions, get in touch with **Pumping Marvellous Foundation.**

Pumping Marvellous
for heart failure patients

Another Mini Toolkit by the Pumping Marvellous Foundation
Crowdsourced information from REAL patients.

Acknowledgements and thank yous

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Nick Hartshorne-Evans Heart Failure Patient, Founder and CEO of the Pumping Marvellous Foundation

Angela Graves Pumping Marvellous Foundation

Contact Us

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✉ **hearts@pumpingmarvellous.org**

▶ **Search ‘Pumping Marvellous’**

𝕏 **@pumpinghearts**

f **Search ‘Pumping Marvellous Foundation’ for our page**

f **Search ‘Help for Hearts’ for our support community group**

Can you help us by donating or fundraising?

This resource has been supplied free of charge by the Pumping Marvellous Foundation. We rely on contributions to help us provide this vital service. Thank you!

Find out how you can support our fundraisers by visiting their JustGiving pages
www.justgiving.com/p-m-f

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Pumping Marvellous
The heart failure charity

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